ADMINISTRATION GUIDE:

Fear of Pain Questionnaire - Adapted for Cerebral Palsy



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What is the fear of pain questionnaire ?

The fear of pain questionnaire assesses pain related fear in children, teenagers and young adults with chronic pain. It can be used by your healthcare provider to better understand your pain and how it is impacting you. It can also help to plan goals for treatment, and make sure goals are focused on things that are important to you. It may also help to work out if there are other health professionals who could help you manage your pain.

How it should be used

Fear of Pain Questionnaire

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2 Pain makes m

 Pain makes me not want to make plans
Pain makes me want to put things off

> in because I think my body will hurt

9 Pain m

- Healthcare providers should explain to the child/young person and family what the purpose of the assessment is
- Most of the time it is easier to complete the pen and paper version before a healthcare appointment. The Talking Mat[®] version might be more suitable for during an appointment

Choosing the best version for you

The fear of pain questionnaire for children can be completed in different formats based on your needs. All versions can be completed with a support person assisting.

- 1. Pen and paper version all questions on one page, pictures included
- 2. Pen and paper version one question per page, pictures included
- Talking Mats[®] version all questions are represented by a symbol





To complete this version you will need to:

- 1. Read and understand questions on a page **OR** understand questions when they are read out loud to you
- 2. Select an option out of 5 on a scale and understand what this means
- 3. Circle a number on the paper

Somebody else can read the questions out loud if needed, or circle the numbers on behalf of the person completing the form.

Talking Mats® version

To complete this version you will need to:

- 1. Look at pictures to help you understand a question
- 2. Listen to the explanation given by someone else (could be a parent, support person or health professional)
- Put the picture under the symbol that best represents you and how you feel **OR** use your eyes to show where you would like to put the symbol

People who need assistance to physically place the symbols can indicate with their eyes, use switches or another method that works for them.

Examples

Here are some examples you can use if the person completing the questionnaire is having difficulty understanding.

"Pain makes me afraid something bad will happen"

= tripping over and hurting myself, having to go to hospital, missing out on something important.

The role of the support person

Both versions can be completed with the help of someone you trust. If you are the support person, your job is to help the person completing the assessment to answer the questions themselves as best as possible. Try not to lead the person into answering a question a certain way.

If the person is having trouble understanding a question, you can provide examples.







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How to set up the Talking Mats® version

- 1. Download picture symbols
- 2. Print off the picture symbols and cut them out
- 3. Choose the pictures that are most appropriate for the person
- Present each picture one at a time. Leave the pictures with the "bite" out of the bottom left corner until last as these are the most difficult to understand
- 5. As you present each picture, ask the following question: "Pain makes me"

"Is it me, sometimes me, not me?"

The person can also place the symbol in between the columns if they are not sure

- 6. Allow the person responding to place the picture under the symbol they think is most appropriate
 - If they cannot pick up and place the symbols, they can indicate with their eyes or by using another method (e.g. switches)
- 7. Give the person time to think and decide where the symbol goes. They can change where it goes at any time
- At the end, go through the picture mat the with person who completed it. Check that they are happy with where they have put the pictures

You could say: 'I want to check that you are happy with where you have put each picture. You said that these ones are you pain makes you [list pictures under that symbol].

These ones are sometimes you – pain makes you [list pictures under that symbol]

These ones are not you – pain makes you [list pictures under that symbol]'

9. Take a picture of the mat and send it to the health care provider involved

We recommend that all people assisting someone to use the Talking Mats version complete Talking Mats Foundation Training to ensure responses are as accurate as possible



Scoring – for health care providers

- 1. Pen and paper: add up the total of items 1-10 (/40).
- 2. Talking Mats[®] framework version:
 - Not like me = 0, Sometimes like me = 2, a lot like me = 4
 - If the person has put an item in between the three categories, then this corresponds to the number in between (e.g. between 'sometimes like me' and 'a lot like me' = 3)
 - Total of all items = (/40)

(22/40)

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Healthcare providers to feedback the results of the assessment, including:

- 1. What the assessment told us about the person's pain
- 2. What the next steps for management/intervention are





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